



Located at
the Mater Hospital,
Level 2, Aubigny
Place
South Brisbane
61- 07-3163 2412
qcidd@uq.edu.au



THE UNIVERSITY
OF QUEENSLAND

May-August 2017

Our aim is to improve the health and wellbeing of adults with an intellectual and developmental disability in Queensland, through multi-disciplinary research, education and clinical practice.

A message from the Acting Director

This is the second QCIDD newsletter for which I've written an introduction since my return to the centre in January this year. I continue to be inspired and impressed by the range of activities carried out by the centre. We offer a clinical service within the Mater Young Adult Health Centre Brisbane. QCIDD staff provide education to doctors and other health professionals. We continue to conduct highly significant translational research focussing on the health of adults with intellectual and developmental disabilities. The environment for our work is dynamic, and significant alterations include the rollout of the NDIS and the centre's increased links to Mater in both clinical service and research.



QCIDD's involvement with the Autism Cooperative Research Centre (CRC) has brought opportunities for collaboration and important initiatives via the CRC include an autism specific CHAP and the "Health Pathways" project in collaboration with the Far North Queensland Public Health Network. Dr Anna Urbanowicz, employed as a post-doctoral researcher on the CRC projects, continues her excellent work in managing the various projects. This newsletter includes brief reports on the activities of our two honours students currently working on Autism CRC related projects, as well as other QCIDD research. We continue to publish significant papers and some of these are highlighted in the newsletter.

We continue to celebrate the successful launch of the Able-X MOOC in 2016, and I congratulate Miriam Taylor and all other QCIDD staff involved in this activity. Miriam's report in this newsletter highlights her diverse and numerous other activities in education and advocacy. QCIDD contributes to the University of Queensland MD program and Dr Matthew Cadman continues to engage enthusiastically as a teacher. Another highlight was the well-attended presentation on autism by Drs Franklin and Sellen at Royal Australian and New Zealand College of Psychiatrists Annual Congress in Adelaide in May 2017.

I hope you enjoy reading about all the above, and other great achievements and activities at QCIDD.

Dave Harley

The QCIDD clinic is located on Level 4, Salmon Building (off Stanley Street) in the Mater Young Adult Health Centre Brisbane (MYAHCB).

If you are wishing to re-arrange an appointment please contact QCIDD on **(07) 3163 2412**.

A warm welcome to Dr Melissa White, our new Psychiatry Registrar. Melissa has worked in other areas within the Mater Health Service. We trust Melissa will enjoy her time at QCIDD.

Dr Matthew Cadman has taken on the education role for medical students. We value his experience in the disability area and he provides a fresh insight for the students.

* * * * *

The current waiting list times are:

- If you have any queries about the QCIDD Clinic, please contact Julie Gibson:

Phone (07) 3163 2524 or email j.gibson2@uq.edu.au.

Page 2

Psychiatry

The QCIDD Psychiatry team were honoured to present at the RANZCP (Royal Australian and New Zealand College of Psychiatrists) Annual Congress in Adelaide in May 2017.

Dr Franklin (Psychiatrist) presented as part of a Child and Youth symposium on "Mental Health in Adolescents and Young Adults with Down syndrome". She reviewed the literature and discussed the upcoming research projects she is undertaking in this area.

Dr Franklin and Dr Sellen (Psychiatry Registrar) presented a symposium on Autism and Mental Health in Adulthood. This was well-attended, with over 270 psychiatrists and trainees present for the 90 minute symposium. This encouraging attendance reflects the growing interest in and recognition of the importance of this area, which traditionally has been under-represented in psychiatric training and experience.



Presentations at RANZCP Annual Congress

Above: Dr Cathy Franklin

Right: Dr Matthew Sellen

Below: Dr Cathy Franklin



QCIDD Research

QCIDD continues to contribute to Program 3 of the Autism CRC that aims to improve opportunities for individuals with autism to successfully transition to post school life, participate in higher education and employment, and identify best practice in health management. In this edition of the newsletter you can read about the preliminary results from our two honours students, who are working collaboratively with the Telethon Kids Institute, Perth, WA, and other exciting projects you can get involved in. We would like to express our gratitude to everyone who has participated in any of these projects for their valued contribution.



Project Updates

Exploring the experiences of autism diagnosis as an adult

This study aims to explore the experiences of individuals who seek an autism diagnosis as an adult. So far, 10 participants have completed an interview. Five have been female, and the ages of the participants have ranged from 38 to 80 years old. Initial coding of the data has revealed some interesting emerging themes. Notably, many the participants involved have reported that they developed coping mechanisms prior to diagnosis. These coping mechanisms can mask autistic traits and delay diagnosis. Another consistent theme identified the importance of developing a sense of trust with the diagnosing health professional. Several participants reported that they had experience with diagnosticians that they did not fully trust, or could not connect with, and this proved to be an initial barrier to proceeding with a diagnosis. Many participants advocated for increased support for diagnostic training to better recognise the presentation of autism in females. As research progresses, more themes will arise for analysis.

For further information please contact: Matthew de Broize (UQ Honours student) at Matthew.debroize@uqconnect.edu.au

Comparing the dental health experiences and oral health needs of autistic adults and the general population

Honours student Prem Brahmbhatt is researching the oral health and dental needs of autistic adults and non-autistic adults. He recently launched an online oral health survey, to build on the findings of a pilot survey about the oral health of autistic adults conducted previously by his supervisors. The pilot survey was answered by 16 participants (12 autistic adults and 4 substitute decision makers) of which five had an intellectual disability. Nine of the participants were males, six were females, and two identified as gender flux. Participants had a mean age of 32.9 years.

Results from the survey showed that four autistic adults required general anaesthesia, sedation or drugs for routine dental care. About 90% of autistic adults disliked and/or were highly sensitive to bright lights, loud noises, drilling, and instruments put in their mouth. Furthermore, 14 participants experienced difficulties in accessing oral and dental care because dental practitioners were not adequately trained in providing special care to autistic adults, and due to a lack of willingness of dental practitioners to treat people with disabilities including autism.

Prem will build on these findings to compare the experiences of autistic adults when accessing oral health services to non-autistic adults. These findings will be used to develop recommendations and interventions dental practitioners can use to improve oral health for autistic adults.

We welcome any volunteers from across Australia willing to participate in our study. For further information please email Prem Brahmbhatt (UQ Honours student) at premkumar.brahmbhatt@uq.net.au

Projects you can get involved in

Comprehensive Health Assessment Program (CHAP) for adults on the autism spectrum with intellectual disability

QCIDD has adapted the Comprehensive Health Assessment Program (CHAP) for autistic adults and intellectual disability and are currently undertaking an evaluation of the adapted CHAP. The evaluation involves the adult visiting their GP to complete the adapted CHAP. This project is an Australia wide project. If you are interested in participating please contact Dr Anna Urbanowicz on (07) 3163 1983 or a.urbanowicz@uq.edu.au

Goal setting tool for adolescents and adults on the autism spectrum

Autism Queensland (AQ) has developed a visual card sort to help adolescents and adults on the autism spectrum participate in goal setting (e.g., for NDIS planning or transition planning). They are seeking feedback on the tool from adults on the autism spectrum (with or without an intellectual disability) and parents of children aged 14 years and over on the autism spectrum (with or without an intellectual disability). The evaluation of the 'Adolescent/Adult Goal Setting Tool' is being funded by the Autism CRC. Participants will receive a \$20 eGift Card for a store of their choice from a selection of outlets. If you are interested in participating or would like more information please contact project officer Vicki Tomkins email: vicki.tomkins@autismqld.com.au or phone: (07) 3273 0000

Australian Longitudinal Study of Adults with Autism (ALSAA)

Researchers from the Autism CRC and the University of NSW are looking for adults to participate in a nationwide questionnaire-based study which aims to improve our understanding of the health and wellbeing of autistic adults and their carers. To be eligible, you must be:

- i) an autistic adult over the age of 25 and living in Australia, OR
- ii) a non-autistic adult over the age of 25 and living in Australia, OR
- iii) a carer or family member of an autistic adult over the age of 25

We are in urgent need of autistic adults to fill out the questionnaire so if you're willing to help or know someone who might be, please contact Ms Jane Hwang or Dr Samuel Arnold at autismcrc@unsw.edu.au or go to this link: https://autismcrc.au1.qualtrics.com/jfe/form/SV_1UoHxIKX4M0WRo1

School Leavers Longitudinal Study

Researchers from the Autism CRC and the Olga Tennison Autism Research Centre at La Trobe University are looking for young autistic adults aged 15-24 years, their parents and young adults from the general population to participate in a nation-wide questionnaire-based study about understanding the process of transitioning from secondary school to either higher education or vocational training/employment for students on the spectrum and their families.

For more information please contact Dr Lauren Hollier or a member of the team at SASLA@latrobe.edu.au

PhD opportunity

A PhD opportunity is available for a highly motivated student to join the QCIDD research team. The PhD candidate will contribute to a project funded by the Autism CRC and must involve the development and trial of resources or programs to enable adults on the autism spectrum to access high quality healthcare.

Applicants will have a primary Honours degree (Honours Class 1 or Class 2A) or a Master's degree in a relevant professional area (e.g., medicine, nursing, allied health or a related science). Strong academic performance and excellent oral and written communication skills are required. Evidence of published research is desirable. Background clinical experience in relevant professional areas would be highly advantageous as would lived experience of autism and a personal commitment to improving the health of people with intellectual and developmental disabilities. Adults on the autism spectrum are strongly encouraged to apply.

A scholarship funded by the Autism CRC is available. This scholarship will have a stipend rate of AUD \$26,682.00 p.a., in line with the stipend rate for the Research Training Program (RTP) scheme. Award of a scholarship will be conditional upon the applicant applying for and obtaining an unconditional offer for entry to the PhD program at UQ. It is expected the candidate will enrol on a full-time basis.

To discuss this role please contact Dr Anna Urbanowicz (a.urbanowicz@uq.edu.au) or Associate Professor David Harley (d.harley@uq.edu.au).

RECENT QCIDD PUBLICATIONS

Enhancing self-determination in health: results of an RCT of the Ask Project, a school-based intervention for adolescents with intellectual disability.

McPherson L, Ware R, Carrington S, Lennox N. *Journal of Applied Research in Intellectual Disabilities* 2017;30:360-70.

What we know

Adolescents with intellectual disability can have a lot of health issues, but often they have problems remembering their medical history and explaining to the doctor how they feel.

What we did

We worked with teachers in schools in Southern Queensland to see if we could help students become more confident going to the doctor. This was known as the Ask Project. We gave the students a health diary and the teachers helped them fill in the details about themselves at school. The teachers also taught them how to be more responsible for their own health. They would role-play going to doctor in class so they could practise making an appointment and the other things they had learnt. They then took the diary home to take to medical appointments as required, and went along to the doctor to have a health check using the Comprehensive Health Assessment Program or CHAP.

What we found

The parents or carers of the 388 students who filled in our survey reported that the students who had been given a diary, were taught the programme and had gone for the health check were more likely to go into the doctor on their own and ask questions and explain their health problems to the doctor, more than two years after the adolescents were taught the programme. The parents or carers also said they had learned some things about the health of their adolescent themselves, and felt more able to help the young person.

Choice making in Rett syndrome: a descriptive study using video data.

Urbanowicz A, Ciccone N, Girdler S, Leonard H, Downs J.. *Disability and Rehabilitation*. Available on-line 23 January 2017, doi:10.1080/09638288.2016.1277392.

What we know

Rett syndrome is condition that mainly affects females. They appear to develop normally in the first months of life before experiencing a regression in abilities such as talking and walking. Very few females with Rett syndrome are able to use words to communicate but many can use eye-gaze or looking to tell people things.

What we did

Researchers in Western Australian have collected information about people with Rett syndrome in Australia so they can understand the condition and help them live a better life. They have videos of some of the females being asked to choose between two or more things such as food or DVDs. We used these videos to describe the choice making abilities of females with Rett syndrome.

What we found

We found that 53 of the 64 females could indicate a choice and most used eye-gaze to do so. Approximately half of these girls or women used more than one way to tell the person what they wanted. Some used words, body movements and other signs. Half of the females, who made a choice, did so within 8 seconds.

We found that all the people supporting people with Rett syndrome used language in our videos to ask the girls or women what they wanted, but they also used actions, signs or symbols. Support persons need to understand that the women or girls can respond to them using their eyes and allow sufficient time for them to do this.

Intellectual disability and patient activation after release from prison: a prospective cohort study.

Young JT, Cumming C, **Van Dooren K**, **Lennox NG**, Alati R, Spittal MJ, Brophy L, Preen D, **Kinner, S**. *Journal of Intellectual Disability Research*. Available on-line 16 Jan 2017, doi:10.1111/jir.12349.

What we know

Studies of prisoners have shown that many have an intellectual disability, but this has often not been identified before they find themselves in prison. Research has also shown that people with intellectual disability can have lots of health issues, but often find it difficult to access health services.

What we did

Our researchers conducted a study of 1325 people leaving prison. Just prior to release they completed a survey which included the HASI (Hayes Ability Screening Index) test to determine if they might have an intellectual disability. They also included a test, the Patient Activation Measure (PAM), to see what they know about their health and rate their confidence that they can look after their health on their own. This test was repeated 1 month, 3 months and 6 months after release.

What we found

The 208 people who the HASI identified as having a disability all felt less confident that they could look after their own health than the other prisoners in the study over the 6 months of follow-up. However, the 125 prisoners who had not been identified as having an intellectual disability before they came to prison, or during their time there, felt even less able to look after their own health 6 months after their release. We think this is because if people are known to have an intellectual disability they do get some support leaving prison. We think that if prisoners could be tested to see if they have intellectual disability when they first go into prison, they could be supported during their time in there and referred on to other services after they leave. This will be particularly important in the future as they could be supported during the NDIS application process to ensure they receive appropriate support on discharge.

Lyn McPherson
Research Coordinator

QCIDD Education

Aside from writing academic articles and managing the MOOCs, the website and social media, Miriam has been attending and contributing to a range of events:

1. Creating Inclusion, Giving Parents a Voice
2. Social Media for Academics and Professionals
3. Learning .uq Basics
4. Learning .uq quizzes
5. Supporting students with disability
6. Queensland Disability Housing Showcase
7. Women and Leadership
8. Towards a Dementia friendly community
9. Princess Alexandra Hospital Health Symposium
10. Social media for teaching
11. The flipped classroom

On 16th May 2017, Dr David Harley and Miriam Taylor presented to the Queensland Disability Advisory Council on invitation about people with intellectual disability in hospital settings. This was our submission but the council was keenly interested in embedding the ABLE X Series of MOOCs in their hospital training.

Kelli Hazard and Troy Hakala of Queensland Health and QCIDD staff are acknowledged for their inputs. Some of the points made by Miriam about people with intellectual & developmental disability (IDD) and their experiences of hospital are summarised below.

People with IDD do not have a high priority within prevention and health promotion programs. Complex, late stage presentations arise from gaps in primary care. Comprehensive health checks would lessen these presentations. When frustrated at not getting message across, people with IDD communicate through behaviour which causes issues in a hospital setting. People with intellectual or cognitive disability access hospital services, particularly emergency departments, more frequently than the general population. Clinicians often lack knowledge about health issues in this population and carers are often sidelined and not allowed to remain with the patient to assist with calming and also communicating important information about the patient's health.

There is no framework in Qld Health for the healthcare of this population. There is also no means of collecting data because Qld Health does not include disability in its data collection systems; therefore we do not know anything about service usage, patient deaths, safety or quality issues. Child Health Qld has workers to assist transition hand-over but adult HHSs do not have intake equivalents to receive the client. Psychotropic medications are used for behaviour management rather than mental health conditions. Health care is not coordinated, and for this population it is essential because they have complex health issues and multiple co-morbidities. Health workers are not trained in managing complex behaviours in a hospital setting; e.g. for a person with autism and intellectual disability who has been waiting a long time in an emergency department, is in pain and cannot verbally communicate this, they may communicate their pain and frustration through their behaviour.

Current strategies include patient passports app developed by West Moreton HHS. There is a QAS emergency paramedicine sheet to help patients without speech indicate what is happening. A validated and evidenced version of a comprehensive health assessment is available through QCIDD.

Resources currently available include Qld Health flu vaccination resources [metrosouth.health.qld.gov.au/sites/default/files/content/flu_vaccination_posters_2016.pdf](https://www.health.qld.gov.au/sites/default/files/content/flu_vaccination_posters_2016.pdf); a Support Worker Health Education Package; the MOOC Education package developed by QCIDD <https://www.edx.org/xseries/intellectual-disability-healthcare>; and Chronic disease programs provided by existing Health & Hospital services. Strategies discussed included developing an overarching QHealth Care Framework to enhance health care services for this population and a disability healthcare access policy which commits QHealth services to making reasonable adjustments to standard care to ensure that people with disabilities can access services such as those legislated in the UK NHS services. Working with QCIDD, PHNs and GPs to encourage the use of the Comprehensive Health Assessment Program (CHAP) to diagnose and treat early-stage conditions would also improve care. Influenza, pneumococcal pneumonia and pertussis vaccinations should be promoted amongst people with ID, carers, support agencies and GPs.

QCIDD links to view at your leisure

- QCIDD's website— <https://qcidd.centre.uq.edu.au>
- QCIDD's person-centred website— www.qcidd.com.au
- ASK Diary (Advocacy Skills Kit Diary) <https://itunes.apple.com/au/app/ask-diary-advocacy-skills/id1095955087?mt=8>
- ABLE101x Through my Eyes—Intellectual Disability Healthcare around the World—
<https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x-0>
- ABLE201x Well and Able—Improving the Physical Health of People with Intellectual Disability—
<https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x-0>
- ABLE301x Able-Minded—Mental Health and People with Intellectual Disability—
<https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x-0>
- QCIDD's YouTube channel— https://www.youtube.com/channel/UChCUpCHdvnHqAf8SBOuV_tA
- Do you have diabetes or do you support someone who does? If so, our free online printable manual, Diabetes to the Point, is available for you here—
<https://qcidd.centre.uq.edu.au/resources/diabetes-point>
- Scared of going for blood tests or CT scans or X-rays? Desensitise yourself here—
<https://qcidd.centre.uq.edu.au/resources/desensitisation-programs>
- Having a yearly health check keeps you well, and here's why—
<http://eshop.uniquet.com.au/chap>
- Tweet to @QCIDD for up to-date news and ideas
- Facebook—<https://www.facebook.com/qcidd.uq>

Other links of interest

- Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland—A systemic advocacy report—http://www.justice.qld.gov.au/_data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf
- Australian Association of Developmental Disability Medicine (AADDM)—<http://aaddm.com.au/>
- Australasian Society for Intellectual Disability—<https://www.asid.asn.au/>